

“*Extended childcare*”?

Reflections on the science of the Zika virus

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Abstract: In 2015, Brazil was the scene of an event that attracted global attention: the Zika virus epidemic. This pathogen arrived in the tropics, bringing with it something new to the Zika medical literature: the birth of children with changes in fetal development resulting from vertical transmission of the virus to fetuses. The phenomenon, which was classified as a health emergency, began to be widely studied and numerous studies were carried out with children born with changes associated with the Zika virus. This article analyzes a set of interviews conducted in 2022 with scientists who were directly involved in the response to this epidemic in the Metropolitan Region of Recife. As the research was mostly carried out with children, we reflect here on how this characteristic permeated the scientific work of the researchers involved. The main objective is to promote broader discussions about the act of carrying out research in terms of urgency, addressing questions about scientific relationships, especially between researchers and participants (Zika researchers and children diagnosed with the syndrome). A second objective is to think about how Child Anthropology can find fertile ground for dialogue with other areas that focus on children and childhood.

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As a start...

The year 2015 was the stage for an event that placed Brazil in the spotlight of global attention: the Zika virus epidemic. This pathogen, originally identified in Uganda in 1947 (Vargas *et al.*, 2016), brought to the tropics a novelty never before recorded in the medical literature, namely, the birth of children with changes in fetal development resulting from vertical transmission of the virus to fetuses. This condition, initially known as the clinical manifestation of microcephaly, has stabilized in the scientific literature as congenital Zika virus syndrome (CZS).

Newborns diagnosed with CZS¹ presented multiple deficiencies that ranged from neurological changes to ophthalmological, cardiac and orthopedic manifestations, among others (Brunoni *et al.*, 2016, p. 3299). This reproductive consequence led the World Health Organization (WHO) to classify the situation as a global health emergency, triggering numerous actions and investments to respond to the situation (Diniz, 2016).

Science, especially in clinical specialties, was directly called upon in the response to the Zika epidemic (Simas, 2020; Fleischer, 2022), taking countless researchers to these children and their mothers, in an attempt to understand how the virus acted in bodies of these newborns. As the research was mostly carried out with children – in this case, children diagnosed with CZS – the focus of this article will be to analyze what it was like, for these scientists, to do research with children so young and with severe disabilities. In other words, we wish to reflect on the scientific relationships that were established between scientists and children with CZS, especially from an ethical perspective.

It is worth highlighting that our research group also fits into this area. For five years, starting in 2016, we visited the city of Recife every six months to monitor the daily lives of children diagnosed with CZS (Carneiro; Fleischer, 2020; Fleischer, 2017). At every visit, the team stayed between 10 and 15 days in the capital of Pernambuco, monitoring the daily lives of children diagnosed with CZS and their caregivers, especially their mothers. Following the inspiration of ethnography, in a total of seven visits between 2016 and 2019, our group attended consultations, physiotherapy sessions, church services, birthday parties and wherever else our interlocutors took us. During this follow-up, we got to know some social actors who, at first, proved to be very relevant and present in the lives of these families, such as journalists, politicians, health professionals, parsons and community leaders.

It was during these follow-ups that we realized how research, scientists and science were intensely incorporated into the daily lives of these families, since, in addition to meeting other research groups while we were carrying out our own, we also heard from mothers that we knew many stories about the strong presence of science in their routines (Fleischer, 2022; Quadros *et al.*, 2020). This scenario took place especially in the first years of the epidemic, when the health emergency status was still in force. Afterwards, many actors who participated so intensely in the lives of these families left the scene, especially representatives of the media, public policy and also some research groups (Fleischer, 2022).

In this sense, in 2018 we carried out a first round of interviews with 13 scientists from Recife who were found through a search for research projects on the Zika virus registered on Plataforma Brasil (Simas, 2020). In 2022, after the initial period of quarantine and social isolation caused by COVID-19, we organized ourselves again for new rounds of interviews with these scientists. This time we re-interviewed some of the people who were previously interviewed in 2018, and we also expanded this network a little and interviewed researchers who were nominated by scientists we had already met. We made two visits to Recife, in May and September 2022, when we conducted 16 and 17 interviews, respectively. In total, 49 interviews were carried out with 40 scientists (nine of which were interviewed twice, in 2018 and 2022).

The interviews, both in 2018 and 2022, were preferably carried out in person, at the location of the interlocutor's choice. Few interlocutors, generally due to the postpartum period or the temporary absence from Recife, requested interviews via remote technology. Knowing their busy schedules and high demand for work during epidemic times, we arranged our presence when it was least intrusive and suggested audio recording. We only negotiate a quieter location to operate the recorders with quality and guarantee concentration and privacy. In general, these aspects were all kindly accommodated without major disruption by the interviewees. Before the interviews, free informed consent forms were read and signed by all scientists. When we conducted the interviews, the project had already been duly approved by our university's research ethics committee.

In our itineraries, we asked questions about the scientists' professional trajectory, how they arrived in the Zika research field, whether they saw similarities and differences between the scientific response during the Zika epidemic and the Covid-19 pandemic, whether they noticed particularities in scientific production

amid health emergencies. We were also interested in understanding how these researchers managed the fact that much of this research was carried out on fetuses, babies and children, since clinical research with this population is surrounded by different regulatory restrictions. In this article, our intention is to make some considerations regarding this specific question, with the aim of reflecting on this mark of scientific dynamics in the field of Zika.

In an integrative review of clinical research carried out with children in Brazil, Jean Vieira and colleagues (2017) searched the Brazilian Registry of Clinical Trials from 1994 to 2014. Of the 187,213 registered studies, only 462 were conducted with the child population (0.24% of studies). In the article, the authors seek to point out some dimensions of what they call the “scarcity” of clinical research with children. According to the group, the scarcity scenario is related to four main reasons: a) restricted number of available subjects; b) high costs of this type of study; c) reduced market for consumption of medicines and technologies; and d) the ethical complexity of research carried out with this population. They also point out that “in Brazil, regulatory initiatives, promotion for clinical research in pediatrics and investment for the training of researchers in the field are non-existent and insufficient” (Vieira *et al.*, 2017, p. 36). Flávia Fialho and Marisa Palacios had also diagnosed a similar scenario, describing a “general reluctance” to involve children as participants in clinical research due to their position as a “vulnerable population” (2014, p. 80).

In a scenario like this, the amount of research carried out with children diagnosed with CZS is impressive. In 2018, for example, a researcher found, in Recife alone, 99 research projects on the Zika virus and the syndrome associated with it (Simas, 2020), most of them involving clinical research with children diagnosed with the syndrome. We can say that Zika science, in general, was characterized by the presence of research participants from the pediatric population. In this sense, paying attention to this characteristic seems to be an important movement to understand the scientific dynamics that influenced the development of this epidemic. This is an important question because, faced with an epidemiological emergency, the focus of studies is, in many cases, on the virus, on finding biomedical, pharmacological answers or a “silver bullet” that takes care of everything (Castro, 2021). And we know that Ebola, Zika and Covid will not be the last emergencies to be faced.

However, we cannot lose sight of the fact that, in the case of health emergencies, the circuit for producing scientific knowledge necessarily passes through the bodies

of sick or affected people. By focusing on the fact that children were the main participants in this research, we are looking at science in a broader and more social way; we are remembering what is at stake in the production of biomedical knowledge: the health, well-being and dignity of its participants. With this in mind, in this article, we seek to turn to the answers that scientists gave us about this hallmark of Zika science, about what it is and what it is like to do research with children diagnosed with CZS.

We begin this article with a brief recap of children's participation in research to briefly show how research with children is, historically, a complex issue, permeated by heated debates and, in general, framed under the category of "ethic". This recap does not have any kind of exhaustive claim or any intention of bibliographical review. We bring these questions as a background, and then, think about how the scientists we know observe and relate to this participation of children as research participants, in which the category of "ethics" was also repeatedly highlighted. Finally, we consider the idea of "empirical ethics" (Willems; Pols, 2010) and Child Anthropology to reinforce the importance and potential of establishing dialogues that are less abstract and principled and more ethical, methodological and contingent with other areas that are also focus on childhoods and children.²

We aim to promote broader discussions about the act of doing research during health emergencies, addressing some questions about scientific relationships, especially between researchers and participants (in this case, Zika researchers and children diagnosed with CZS). However, it is worth highlighting some limitations: until now, our research has focused largely on research projects and investigations anchored in biomedicine. Therefore, the discussion presented here cannot be extrapolated to investigations in other areas that were also dedicated to the epidemic, such as Social Work, Law, Education and Anthropology itself, an area from which both authors position themselves. In fact, we intend, at another time, to bring all these issues back to our own practices, something that was not done for this article. Finally, it is worth highlighting that the text does not analyze in depth the 49 interviews carried out within the scope of the project, as we chose to delve a little deeper into a smaller set of interviews. The material, however, is very rich and useful, and will continue to be analyzed by the team for future reflections and publications.

Children's participation in research: a brief review

To think about children's participation in research, it is first necessary to define which research and areas we are referring to. In the case of Social Sciences, especially in Sociology and Anthropology, children were included late in research, having historically occupied a marginalized place with little relevance to social life (Buss-Simão, 2009). Scholars of childhood and children report that, when Sociology and Anthropology were consolidated as academic disciplines, the child was seen as a “biological package”, coming almost entirely from nature and biology, a framework that did not arouse the interest of analysts of society and culture.

Later, with the appreciation of fieldwork engendered by British functionalism and American culturalism, children began to occupy more pages of books, articles and essays (Mead, 2001; Benedict, 1947). Initially, however, its location was in terms of socialization. From this perspective, the child would not only be “a biological package”, but also a cultural and social “receptacle”, an approach that located them as an incomplete being, an adult-to-be, while adults would be full subjects in fact (Pires, 2009). This scenario began to change especially in the 1980s, when an interdisciplinary group of intellectuals interested in children developed what they called the “new paradigm” of childhood. In this new paradigm, children not only occupy the place of “recipients” of culture and socialization, but are now seen as active social actors in the production of culture and society (Prout; James, 1990).

In the case of Biomedical Sciences – an area with which our current research maintains a strong interface, and which will be the focus of the review from now on – the status of children in scientific research practices has also changed over time. Until the 18th century, documentation on pediatric research was scarce. Moreno and Kravitt (2010) explain that, at that time, the physiology of children and adolescents was not explored, a situation that we can link to the fact that, in Western societies, children did not yet have a differentiated status, as shown in the historiography of Philippe Ariès (1981). With the advancement of differentiation between children and adults, however, medicine aimed at children began to consolidate in the 19th century, resulting in the creation of the first pediatric hospitals. Alongside orphanages, hospitals became spaces where large groups of children could be evaluated, monitored and, in many cases, used for medical experiments, which positioned children as “desirable candidates” for research (Moreno; Kravitt, 2010, p. 55).

At that time, there was little or no concern about the consent of research participants, whether adults or children. Investigations conducted at the end of the 19th century and the beginning of the 20th century rarely considered the possible risks and discomforts of research participants. Research into developing vaccines and understanding child physiology has been widely conducted in orphanages and prisons, for example, often resulting in discomfort, health problems and, in some cases, even death.

With the Second World War, a new wave of research was formed, and, once again, children were considered “desirable” subjects. The easy manipulation of their bodies generated desired control for researchers and many of them became research participants in the name of war, without any possibility of authorizing or denying participation in such experiments. In addition to the war, events such as the Willowbrook study, in which children from an American orphanage were purposely contaminated with the hepatitis virus, also shed light on the inappropriate inclusion of children in experimental research. The Tuskegee study (Reverby, 2010), although not carried out with pediatric participants, also brought into focus the exploration of vulnerable and racialized populations for research purposes.

The exploitation of research participants was the center of the trial of Nazi doctors for crimes committed in the form of clinical experiments, which took place in 1947. The trial gave rise to the Nuremberg Code, considered the first document to list common principles for the ethical conduct of experiments on humans. The first principle of the code states the voluntary consent of research participants as absolutely essential. The judges of the Nuremberg court directed the principles exclusively to adults, thus prohibiting the participation of children in medical research, since children would not have the legal autonomy to consent.

The code, however, did not have satisfactory regulatory effectiveness and much research involving human beings – including children – continued to take place without concern for the principles listed in the code. Despite this, the Nuremberg Code sparked intense discussion in the scientific community, especially among doctors. These professionals debated the implications of the principles mentioned in the code for carrying out research. Susan Lederer (2003) recovers, for example, a manifestation by Henry Beecher, anesthesiologist. In 1959, the doctor wrote that the implications of Nuremberg would restrict the possibility of research into mental illnesses, a consequence also transposed to other studies, as in the

case of studies with children. Beecher's concern was based on the possible risks of applying treatments and therapies to this population, since there would be no studies to evaluate efficacy and safety, an issue that was also addressed in the 1964 Declaration of Helsinki, considered as the second document to list standards and principles for clinical research.

In addition to bringing into debate the dangers of a lack of research with certain populations, the Declaration of Helsinki also stipulated a differentiation between therapeutic research – when there is evidence that the intervention could benefit, individually, the research subject – and non-therapeutic research – when there is no prediction of direct benefits. Both types of research could be carried out with children, as long as their parents or legal representatives gave consent. In 1974, another milestone for research with child participants came from the creation, in the United States, of the National Commission for the Protection of Subjects in Biomedical and Behavioral Research, which prepared recommendations on research regulation.

At that time, two theologians were involved in a controversy regarding research with children. As theologians, both were concerned about the morality of conducting research on pediatric participants. While Paul Ramsey argued that research on children should be banned absolutely and conducted only when there were direct benefits to the participating children, Richard McCormick argued that research on children was not only “morally permissible, but morally obligatory to improve health and well-being of children”, with the consent of parents and legal guardians being sufficient to conduct investigations (Moreno; Kravitt, 2010, p. 57).

The National Commission for the Protection of Subjects in Biomedical and Behavioral Research also introduced, in 1978, the Belmont Report, another celebrated document in the field of research regulation. This report also stated some principles, recommending that, in research with human beings, there must be respect for the people involved. Respect, according to the report, has two components: treating individuals as autonomous agents and that people with less autonomy should be protected – which includes children. According to the report, to protect them, informed consent, permission from parents and legal guardians and the assent of the “minor” come into play. Furthermore, the report also advocates the benefit principle, as advanced by the Declaration of Helsinki. And finally, the report brings justice as a principle, understood as “fairness in the distribution of the burdens and benefits of the research effort” (Moreno; Kravitt, 2010, p. 57, free translation).

In Brazil, the research regulation system began its emergence process in the 1990s, when the National Health Council (CNS) created, through Resolution no. 196/96, the National Research Ethics Commission (CONEP). With the Resolution, CONEP is responsible for formulating and updating general research ethics guidelines, functioning as a guide for the Research Ethics Committees (CEP), a system known as CEP/CONEP. In addition to Resolution no. 196/96, it is also worth mentioning Resolution no. 510/2016, designed to guide and direct research carried out within the scope of Human and Social Sciences. Among the guidelines set out by all these resolutions are the requirement for consent, minimization of risks, maximization of benefits and respect for research participants. In the case of research with children, the CEP/CONEP system also requires the consent of parents or legal guardians, and also requires assent for children who are able to do so. The National Council for the Rights of Children and Adolescents (CONANDA) also elaborated some reservations regarding research with hospitalized children, emphasizing that they have the right not to be the subject of clinical trials without the informed consent of their parents or guardians and their own, when they have the discernment to do so.

Children, therefore, often took the place of research participants, not always having their integrity preserved, valued and protected. Because they are considered a vulnerable population, pediatric patients – and research participants – have occupied specific positions in codes, resolutions and statements regarding research with human beings. In this sense, the issue of carrying out research with direct intervention on children's bodies has countless layers, stories and disputes that were, recurrently, framed in terms of “research ethics”. On the one hand, the ethical debate focuses on the protection and non-exposure of children; on the other, many argue that the use of children in research would be ethical precisely because it contributes to the development of biotechnology for children and humanity. The fact is that clinical research with children is a thorny and complex topic.

These debates, however, tend to gravitate around what Pols and colleagues call “big questions” (Pols, 2015) and themes, in which the values of what is “good” are defined *a priori* and in advance, in a prescriptive manner, normative and principled. Resolutions, guidelines and declarations therefore seek to outline general and universal principles for the proper conduct of research. These elements are important, especially after so many abuses in the history of medical research, and

it is not our intention here to take any position contrary to the existence of general regulations and protocols.

However, despite the relevance of general principles, in this article we wish to think about research ethics in a more microsocial, localized, positioned way, starting from the field and specific dynamics of the science of the Zika virus in the Recife region. Still following Pols (2015) and her colleagues (Willems; Pols, 2010), our movement here meets the empirical turn proposed by these and many other authors. For them, the so-called “empirical ethics” would distance itself from the analysis of the formulations of normative criteria to define what is ethical – what the authors call normativity –, moving closer to more local, more practical definitions – what they call intranormativity. In other words, the empirical turn concerns the “everyday work of groping for good care in various, sometimes completely prosaic, forms” (Willems; Pols, 2010, p. 163, free translation). It is also worth highlighting that, for the present article, we dialogue in a more articulated way with the discussion that Jeannette Pols and her colleagues have been developing around the category of “ethics” and “empirical ethics”. There are, however, other ways to deepen this analysis, which we intend to return to in future work, as in the case of discussions articulated in the field of bioethics (Rego; Palácios; Siqueira-Batista, 2009).

Following Pols’s proposal, we wish to focus on the different – and sometimes conflicting – practices of what is ethical for the scientists we know. In other words, our objective is to move from *general normativity* to *local intranormativity*. A normativity that is not external to scientific practice, but internal to it and that emanates from it. The debate on ethics, in this sense, expands and pluralizes and takes on practical and local contours and positions, as Pols suggests, ethics in the world. In this case, in the world of research carried out with children in the field of the Zika epidemic. It is with this in mind that, below, we look at the interviews carried out with scientists who participated in research on Zika and its congenital syndrome. That is, how did these scientists from Recife think about and address the challenges posed by research with children?

Children’s participation in Zika virus science: what do scientists say about CZS?

Contrary to the scenario described by Vieira and his colleagues (2017) regarding the low amount of clinical research carried out with children in Brazil, the Zika

epidemic resulted in a true wave of research carried out with this population. Children diagnosed with the syndrome were researched by different areas and, consequently, were exposed to different types of instruments, exams, devices, tests and degrees of monitoring, such as anthropometry assessments, MRIs, CT scans, x-rays. One of the scientists we interviewed even defined the situation as a “cry for children” to do research.

The science of Zika, as we mentioned in the introduction, was a science carried out with children and, in this sense, an attentive and careful analysis of such dynamics can have a positive effect on a broader reflection on the practice of science with this population. It was against this backdrop, therefore, that we added a specific question to the interview guide about this striking characteristic of scientific research in the field of the Zika epidemic: are there particularities in carrying out research with children? Which? With this question, we wanted to understand what it was like to do research with children for this diverse group of scientists that we know.

In this article, we will focus on their elaborations on this question. As in the review outlined above, many of the responses from our interlocutors also revolved around the ethical issue regarding research with children. But what is seen as an “ethical” debate and what is considered “good” was filled in different ways, some more abstract, others more practical. Before moving on to an analysis of the responses, it seems important to describe, albeit briefly, who are these 40 scientists that anchor the observations in this work.

In terms of specialties, we know professionals from 17 specialties: Social Demography, Epidemiology, Physiotherapy, Obstetrics, Biomedicine, Social Work, Psychology, Dentistry, General Practice, Infectious Diseases, Neurology, Nursing, Nutrition, Occupational Therapy, Speech Therapy, Gastroenterology and Otorhinolaryngology. Of those interviewed, few declared themselves as “white”. The majority declared themselves as “black”, “brown”, “mixed race” and “yellow”. Of the scientists interviewed, 31 were women (which is why we adopted the feminine plural to refer to them).

Some of our interlocutors did not meet the children directly affected by the Zika virus epidemic. For example, they analyzed organic substances that had already been collected from children by other colleagues on the team or from other teams. Or they prioritized computerized studies, which simulated the virus’s behavior using

modeling systems. Or they focused on bibliographic, archival and retrospective studies (such as medical records, statistics, for example).

Many others, however, received the children in their offices, took anamnesis, collected or directly instructed the collection of organic materials (blood, plasma, CSF, urine, above all, see Fleischer, 2023). They acted, at the same time, as health professionals who monitored the care of these children as patients and as researchers who also looked at the data issued by these children as research subjects. Despite differences in specialty and style of contact with research participants, both types of scientists considered, in their responses, the participation of these subjects in terms of “research ethics”. And, as we will try to show, the elaborations of “ethics” were fulfilled in different ways.

Ethics in research with children diagnosed with CZS: from committees to practice?

As we mentioned, the ethical particularities of research with children are a milestone in the regulation and regularization of research carried out with the child population. Children are located as special and vulnerable populations, a situation that poses new layers of ethical care, as mentioned above. But what about the CZS scientists? How did they locate the ethical issues in their research? When answering the question that is the object of analysis of this article, almost all researchers were categorical in differentiating between researching with children and adults.

The exception came from a biomedical doctor, whose research involved more intensive bench research. She emphasized that: “when the blood comes to me, so I can extract the DNA, it doesn’t matter if it’s an adult or a child, it’s all the same.” For this biomedical doctor, the difference in research with adults and children in her area was located exclusively at the time of extracting the child's blood:

The baby moves, right? A little child moves! I actually picked up a little baby, so collecting it is very difficult for you. And you have resistance, right? So, the mother is like, “Oh, how long will it take?” Then you get... It has to be a specific needle, you also had to buy a specific needle for them. So, until collection yes, then no! (Excerpt from interview with biomedical doctor, May 2022).

For the rest of the researchers, whose research involved more prolonged physical contact with the participants, the difference between adults and children was noted with different degrees of emphasis: from “it’s definitely different”, as a physiotherapist

told us, to “there are some questions, scales, questionnaires and instruments that are different, that are specific to children and adults”, as a gastroenterologist put it.

This difference was, in many of the responses, an immediate association with issues relating to research ethics, as in the case of an otorhinolaryngologist, who began her response by saying that “we need to be very careful with the ethical issue, right? As we do with adults, but it is doubled with children”. The extra care, according to the doctor, comes from the double layer of consent, which involves not only the child, but also “the consent of the parents, whoever is there guiding the child”, she added.

Another doctor, a gastroenterologist, also directed the particularities of research with children to the ethical dimensions in terms of consent that pediatric research involves: “Research with children begins by never involving just one subject, right? In pediatrics, you will always have at least one extra family member or guardian, right? So, even in terms of ethics, consent, all of that.” Many of the researchers, in this sense, emphasized that, in research with children, it is necessary to develop the ability to communicate the possible benefits for the caregiver, for the parents, for the legal guardian. This formulation was once again emphasized by a neurologist we know: “Doing research with children from an ethical point of view is that, it means knowing how to communicate and clarify expectations, so that the family is aware of what is being done”.

The issue of consent from legal guardians is a principle that guides research ethics committees, since, legally, children are considered incapable of consenting – as, in many cases, they may not satisfactorily understand the risks and benefits of their own participation. For sociologists, anthropologists and other intellectuals involved in the new studies of childhood, this location of the child as “incapable” is related to the conception of childhood as a “blank slate”. Starting from the paradigm established by childhood studies, however, children come to be seen as social actors, endowed with agency. In this sense, childhood scholars argue that children, depending on their age, can understand the explanations of research conductors, even emphasizing that children participate in the stages of research development, in an approach that considers them as co-producers of science.

In the case of Zika, however, this issue gained more complex contours, since, in addition to being very young children at the beginning of the epidemic (2015-2016), they are also children with severe cognitive disabilities, which, as described by a

gastroenterologist we interviewed, “there is no way to speak or nod”. The fact that the child cannot nod, for this doctor, cannot be resolved simply with the authorization of the legal guardian. This would be an initial step, an assumption, since, although children cannot verbally consent, there are other ways to assess a child’s comfort or discomfort during a given protocol. For this doctor, it is important to establish a relationship with children, to actually interact with them and try to learn about their sensations, pleasures and discomforts.

That was why, in her master’s research, she chose not to use the technique considered the gold standard for evaluating gastric motility³ in children with CZS, precisely because it was more uncomfortable. As a solution, the researcher opted to use ultrasound. This technique is also consensual among peers, but it does not require the placement of probes or tubes nor does it involve exposure to radiation, which makes the assessment safer for children. In other words, the gastroenterologist in question worked within what her field recommends, but taking into account the children’s perspective and sensations – and considering, especially, that many children would not only go through her research protocol, but also that of many others who surrounded the Zika epidemic. This concern is also ethical because it considers that, in an epidemic context, much research is underway on the same, finite set of bodies in that region. This doctor perceived herself as participating in a broad network of scientific efforts in Recife. And she realized that children were also collaborating with science in many other networks.

Martin Woodhead and Dorothy Faulkner (2000), in a text that reviews some research methodologies carried out with children in the area of Developmental Psychology, also bring some provocations about how children can, non-verbally, demonstrate their non-assent. Crying, discomfort, palpitations and signs of stress, a whole non-verbal language that, due to the recognition of this research participant in his corporeality, may also have been valued by the gastroenterologist mentioned above.

Here, the ethics around consent is no longer discussed based on more regulatory and protocol issues, and is brought to the practice of research, to the way in which children were crossed by techniques, instruments and methodological choices to access the Zika virus. In other words, the doctor in question helps us think about ethics in a more prolonged way, helps us to visualize it in practice at all stages of research, not just in its preparation, approval and permission. Although the gastroenterologist referred to consent in her bureaucratic framework, mentioning

the importance of the Ethics Committee and free informed consent forms, her speech also brings consent to the practice, it also helps to illuminate the "ethics in the world" of children with CZS, as call Pols and colleagues (2010), and not just "in the world of the CEP/CONEP system".

Other scientists also took us, in their interviews, to more local, more everyday situations about "ethics in the world" of pediatric research. Previous experience with children, for example, was also highlighted by some scientists as an issue that interfaces with ethics. Many researchers who looked into the virus and the syndrome associated with it, as they told us, had never worked with children before. This lack of experience is translated into possible risks that this lack of practical knowledge with children can generate. By not knowing how to "reach the child", for example, as a physiotherapist we know said, the researcher can create situations of stress, discomfort, mistrust and even trauma for the little patient. For her, knowing how to reach children involves knowing how to captivate them, approach them carefully, calmly, in a construction of a scientific relationship that demands time, contact, trust and continuity.

Here, the experience with children fits the ethical debate in the relationship built between the research subject and the research subject. Pediatric specialization, for this physiotherapist, was a necessary requirement for the design of appropriate and suitable methods for the subjects as they attend the clinic and/or research. This physiotherapist's vision was shared by a colleague from her master's class who also participated in research with children diagnosed with CZS. For her, many researchers were not "knowing what to do", because they had only attended and carried out research, until then, with adults.

Carrying out research with children, for her, involved a series of instrument adaptations, placing playfulness and play as important elements to develop methodological and ethical research centered on children. For example, games, humor and informality help to establish contact, create bonds of trust, horizontalize exchanges, open up the possibility of dialogue, including the sensitivity to perceive any expression of discomfort and non-consent, for example. This contribution is also very close to the discussions carried out by Anthropology, by considering, in the methodologies, the diversity of children's experiences and the diversity of sociocultural contexts of childhood. The anthropological approach seeks to deconstruct a notion of "universal child", seeking to emphasize the different ways of being a child

and experiencing childhood, recognizing the alterity, the diversity of this “other” (Fonseca; Cardarello, 1999; Rifiotis *et al.*, 2021). As in Child Anthropology, which advocates looking at the local and particular realities of children and childhood, our interlocutors were drawing attention to different ways of being a participant in pediatric research.

This adaptation and recognition of the “pediatric other”, however, did not always occur. As the physiotherapist said, many researchers had never worked with children before. In practice, this can result in uncomfortable interactions, as mentioned by the physiotherapists above, but it may also have had deeper impacts on the care provided to children diagnosed with CZS. The lack of experience and understanding of what it meant to work with children was framed by another physiotherapist based on the inadequate temporality of much of the research carried out on Zika virus. Many of them, argues the interviewee, did not provide for longitudinal monitoring:

Because you cannot work with childhood without thinking about the longitudinality of care. So that's it, at the time, there was this policy of imaging exams, doing I don't know how many images, doing hip [surgery], doing I don't know how many [exams]. Yes, so what? And then, tomorrow, right? There's this. Where is the research with children now, right? Where are they now? So, of course it was research that was useful, but it didn't have an application when we think about the importance of longitudinality in research and assistance. A child is not a small adult, right? So everything we do now, I need to think about the medium and long term, right? (Excerpt from interview with physiotherapist, May 2022).

For this physiotherapist, many scientists who were not familiar with the world of children, driven by the scientific opportunities offered by the epidemic, “surfing the crest of the wave” and carried out research without actually worrying about the results for children. Some researchers have already discussed the “scientific rush” that happened, for better or worse, in the Recife territory in times of the Zika epidemic (Quadros *et al.*, 2020; Matos; Rodrigues, 2021; Fleischer, 2023; Löwy, 2019). In addition to the waves, which are generally fleeting and only surfed by a few, this physiotherapist we interviewed emphasized that, when dealing with children, science and assistance must necessarily involve *longitudinal monitoring*. In other words, in the day-to-day life of the clinic, these children grow and need to have their new developments and needs met constantly over time. The physiotherapist in question criticized research that was carried out in the heat of the moment and then “disappeared”.

In general research contexts, this practice would already be considered problematic, but in a child health context it becomes worse, as their bodies demand continued, more attentive monitoring. This was an issue also noted by the mothers of children diagnosed with CZS. As the research was carried out, many of them began to question the design of the projects, especially in terms of longitudinality that the physiotherapist mentioned above. In fact, the mothers of children diagnosed with the syndrome played an important critical role in relation to the scientific practices of the Zika epidemic, often helping scientists to redirect and readjust their projects (Fleischer, 2022; Matos; Silva, 2020).

Steven Epstein, a scholar of another epidemic, that of HIV in the USA in the 1990s, had also pointed to a certain “flood” of research carried out during health emergencies, in which new notices, financing and resources are made available. In fact, in dialogue with the discussion about specialization as an ethical interface that we brought up in the statements above, Epstein also commented that emergency contexts can “promote research by people who simply have not taken the time to get to know and learn about the communities they want to study” (2008, p. 807, free translation). And, we add, they also did not take the time to get to know and learn about what and how to give back to these communities once the research was completed. Epstein, based on HIV, and some of our interviewees, based on Zika virus, drew attention to how scientific relationships should begin before and end after the research project itself. Therefore, they are drawing great attention to the relational aspect of science. And they are pointing out how childhood demands specific research designs, perhaps even more intensely relational.

Ethical issues, therefore, were addressed and brought into practice in different ways by the scientists we met in Pernambuco. In this section, we seek to present some of these ways, weaving some approaches and dialogues with some issues in the Sociology and Anthropology of Children. We believe that observing and understanding how science has looked at children's bodies in the context of the Zika epidemic can create broader, more powerful echoes that can reach other research with children.

To conclude...

In this article, we brought some interpretations about research with children based on a specific question asked to Zika scientists in the Recife region, one of the significant epicenters of the epidemic between 2015 and 2016. For many of them,

research in the pediatric scenario refers, above all, to the topic of research ethics. It was possible to perceive an interesting connection between ethics and methodology, two issues that can even be thought of collectively as “ethical-methodological” issues (Sousa; Pires; Amoras, 2021).

On the one hand, what worried them most when taking children’s bodies as a starting point to understand a health phenomenon is that the objectives, motivations and procedures respected those recommended by the CEP-CONEP system in the country. At first glance, it seems that they are guided by what was agreed upon and suggested by the resolutions that came from the CNS and CONEP. On the other hand, however, looking more sparingly at what the interviewees explained to us, it seems that ethical issues, when considered beyond more protocolary moments such as committees and terms, slide with some ease into the methodological, technical, instrumental and relational aspect of research. In other words, the scientists’ responses reinforce us that methodological steps must be thought of from an ethical perspective, which takes into account the particularities, subjectivities, preferences and discomforts of the subject in question, a context that places ethics in a more empirical, more procedural way (Willems; Pols, 2010).

Thus, based on an idea of “empirical ethics” by these two Dutch authors, the abstract idea of “ethics” is filled with values and care perceived by scientists as they lived and live with these children. It gains a more practical and concrete portrait of the Recife scene. Still, this research with children focuses a lot on the “ethical” (or “ethical-methodological”) aspect – the planning and development of the research project – and not so much on the subsequent developments of the research – the results and evaluations of the research project. Before and during, not so much after, as recalled by the physiotherapist concerned with long-term clinical care.

In this sense, Child Anthropology – which records the diversity of children’s childhood and life experiences – can emerge as an important partner for reflecting on ethical-methodological issues not only in Social Sciences research, but in clinical and biomedical research as a whole. Alan Prout (2010), for example, has already mentioned the need to establish more direct and more intense dialogues with the biomedical areas that focus on childhood, often marked by the suffix of pediatrics (Infectious Diseases, Neuropediatrics, Gastropediatrics, etc.). Here, we are suggesting more creative partnerships, such as an anthropo-pediatrics or an infectious-anthropology, for example.

In this article, we suggest that a good channel for this dialogue may be precisely ethical-methodological questions, in the sense of not only abstractly projecting what would be ethical, but also how this ethics will manifest itself in methodological practice and in questions of schedule and return, in order to increase the times in which care and research results are considered. This debate, in addition to expanding the focus of reflection in relation to research practices, is also important because of the direct impact it can have on the way children, as full subjects, experience science. Illuminating this debate, therefore, is also a way of improving science for scientists, but, above all, for children.⁴

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Notes

¹ The correlation between Zika virus infection and the birth of children with microcephaly and other congenital abnormalities was the result of an intense research process that is well described in Diniz (2016) and Löwy (2019).

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³ Gastric motility refers to the contraction of a specific muscle (the smooth muscle) in the walls of the gastrointestinal tract. This contraction moves, mixes, grinds and stores food in the gastrointestinal system.

⁴ T. Valim e S. Fleischer: conception, analysis and interpretation of data; writing the article and final approval of the version to be published; responsible for all aspects of the work in ensuring the accuracy and integrity of any part of the work.

Resumo

“Cuidados redobrados com a criança”?

Reflexões sobre a ciência do vírus Zika

Em 2015, o Brasil foi palco de um evento que despertou a atenção global: a epidemia do vírus da Zika. Esse patógeno chegou aos trópicos trazendo consigo uma novidade para a literatura médica do Zika: o nascimento de crianças com alterações no desenvolvimento fetal oriundas da transmissão vertical do vírus para os fetos. O fenômeno, que foi enquadrado como uma emergência em saúde, passou a ser amplamente estudado e inúmeras pesquisas foram desenvolvidas com as crianças nascidas com alterações associadas ao vírus Zika. Este artigo analisa um conjunto de entrevistas conduzidas em 2022 com cientistas que estiveram diretamente envolvidas na resposta a essa epidemia na Região Metropolitana de Recife. Como as pesquisas foram majoritariamente realizadas com crianças, refletimos, aqui, como essa característica atravessou o fazer científico das pesquisadoras envolvidas. O objetivo principal é promover discussões mais amplas sobre o ato de fazer pesquisa em termos de urgência, direcionando questões acerca das relações científicas, sobretudo entre pesquisadores e participantes (as pesquisadoras do Zika e as crianças diagnosticadas com a síndrome). Um segundo objetivo é pensar como a Antropologia da Criança pode encontrar um terreno fértil de diálogo com outras áreas que se debruçam sobre crianças e as infâncias.

► **Palavras-chave:** Ética em pesquisa. Crianças. Zika Vírus. Recife.

